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ABSTRACT

A qualitative study of three adults with Asperger Syndrome consisted of interviews conducted in person, over the phone, and via e-mail for 9 months. A main theme of the study was that they wanted to be considered experts in the field of autism and be consulted on issues related to autism. Consequently, these adults were asked to be part of a course at the University of North Dakota that provides parents, teachers, and caregivers of individuals with Asperger Syndrome with knowledge and experience of diagnosis and characteristics, assessments, functional analysis, methods, and support for families. This online course has a Web site that includes audio power-point lectures and other materials that are downloaded for each week's chat session. The adults did two interviews for the class. One was about their experiences growing up, their families, and their school experiences. The other was about their experiences transitioning into the adult world and what it was like being an adult with autism. After the interviews, students e-mailed questions to the adults, who replied promptly, sharing advice and personal thoughts on the subjects. The students found the input of the three adults extremely valuable and have asked them to fly to North Dakota for speaking honorariums. There are also plans to have these adults "log on" as co-teachers during chat sessions and participate during live discussion. (TD)

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ADULTS WITH ASPERGER SYNDROME: HOW THEY HAVE HELPED MY TEACHING

In the recent past, there has been increased interest in learning more about adults with autism. More articles, books, and stories have been published, and these adults, particularly those with high-functioning autism or Asperger Syndrome, are frequent guest speakers and panel members at national conferences on autism. They understand the value of having parents and professionals learn from them and see the need to educate others about autism (Hurlbutt & Chalmers, 2002).

This article is a discussion of how the author met three adults with Asperger Syndrome and developed friendships with them, and how all four of them continued to work together to educate others about autism.

Because of the author's interest and background in working with adults with developmental disabilities, including those with mental retardation, autism, and other related disorders and disabilities, she wanted to further explore the lives of those with autism, what they have experienced, what their thoughts and feelings were on a wide variety of topics, and how they felt about having autism. It would be necessary to work with individuals at the high end of the spectrum for the purposes of in-depth interviewing.

The incidence rate of Asperger Syndrome in North Dakota is increasing just as it is in the rest of the country, however, in this rural state, there are very few known adults diagnosed as having Asperger Syndrome. At the time of the original study (1999), the researcher was aware of only one. The Autism Society of America hosts a national conference each year and this was selected as the setting for the initial interviews for the study.

The original study

At the beginning of the conference, the author was approached by one adult with autism who recognized the hometown written on the nametag (Fargo) as being the name of a movie – Fargo! There's a movie called Fargo! *The two continued to talk and explain why they were there. When this adult heard that the researcher wanted to interview adults with Asperger Syndrome, she graciously volunteered and promptly introduced the author to two others who also volunteered.*

The initial visits were held during the conference and lasted approximately two hours. The author and the participants visited informally at other times during the conference as well. Over the next nine months, follow-up interviews were conducted over the phone and via e-mail. Each participant also shared copies of various articles, stories, and essays they had written over the years. Qualitative research methods were used for this study and notes and data were kept over the course of the nine months. Data were analyzed using qualitative research methods, including coding by paragraph, using key words that expressed the main ideas and clustering them into codes, which were collapsed into categories. From there, three main themes emerged from this data. The results of that study included the following themes:

1. High functioning adults with autism identify with their own unique culture (they view neurotypicals, i.e., persons without autism, as narrow-minded and they have no desire to be neurotypicals).
2. Support systems contributed to their feelings of self-worth (they believe that positive family involvement and support help individuals with autism develop skills necessary to be as successful as possible as adults and that the spiritual aspect of their lives and their connection to a church provided comfort and support).
3. They have developed opinions on a wide variety of topics, especially those related to autism, and have suggestions for what could make a difference in the lives of people with autism (group living arrangements and activities are dehumanizing, unemployment and underemployment are real problems for

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people with autism, behavior issues need to be addressed individually and positively, individuals with autism need support to develop social skills). (Hurlbutt & Chalmers, 2002)

The online course

The overall main theme from this study was that they wanted to be considered experts in the field of autism and be consulted on issues related to autism. This theme was the basis for asking these adults to be a part of the course the author teaches at the University of North Dakota. The course is called "Methods for Students with Asperger Syndrome." It is an elective course in the sequence of interdisciplinary courses focusing on autistic spectrum disorders (ASD), specifically the students who function at the high end of the spectrum. The purpose of this course is to provide parents, teachers, and caregivers of individuals with Asperger Syndrome with background, knowledge, and experience with the diagnosis and characteristics, assessments, functional analysis, various methods and practices, transition planning, and support for families.

North Dakota is a rural state and it is a challenge to provide educational opportunities to teachers and college students all over the state, especially about a low-incidence disability, like autism/Asperger Syndrome. Sometimes, when a student with autism or Asperger Syndrome moves into a school district in rural ND, he or she may be the only student with autism the school will ever have! Or it may be ten years before another student enrolls in that particular school. The nearest city may be 200 miles away, which makes it almost impossible for parents and school professionals to obtain needed information. They resort to paying for consultants from the larger cities to provide short-term support and recommendations for school programming. The University of North Dakota now offers a certificate in autistic spectrum disorders, all conducted online. This program was developed by Dr. Marjorie Bock of the University of North Dakota.

Each of the courses has a website which students (who are usually teachers and parents from around the state and nearby Minnesota) utilize to view and listen to audio power point lectures and other materials that are downloaded for each week's chat session. Small groups of students log on each week and "chat" about the topic of the week and share ideas and suggestions with each other.

After the original study was completed, the author and the three adults continued to stay in contact, mostly through e-mail. The adults talked about the conferences at which they presented, the trips they took, the weather, politics, current events, their families, and relationships. Their interest in wanting to continue spreading the word about autism and being a part of new opportunities to do so was ever-present. When the author started planning for the new "Methods for Students with Asperger Syndrome" course, she felt it would be a great benefit to this course to have the three adults serve as guest lecturers, or co-teachers.

All three adults were very interested in being a part of this class. Even though they had participated in intensive interviewing for the original study, they agreed to do two interviews each for the class. The first set of interviews was about their experiences growing up, their families, their school experiences; and the second set was about their experiences transitioning into the adult world and what it was like being an adult with autism.

Also, all three communicated with the students in the class via e-mail. The students e-mailed them about questions they had regarding programming, social skills, vocational training, behaviors, etc., and the adults responded to each of the e-mail questions, promoting other questions and more communication between the students and the adults with Asperger Syndrome. The three adults are Xenia, Joe, and Eugene (pseudonyms). Xenia is in her 30's and lives in a city in the interior west section of the United States. Joe is also in his 30's and lives in a city in the Midwest. Eugene is in his 60's and lives in the northeast section of the United States.

In the first set of interviews, they talked about what it was like for them growing up, what their families did for them, how they did in school, what problems they faced in school, and how they overcame some of the problems. The following is some of the information they shared in their interviews for this course.

Xenia

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Xenia shared that she was from a large family of eight children and that, when she was tested at age 3, her IQ was reported to be 48. She did not start talking until age 4. She knows she *would have been institutionalized* if she did not start talking by age 5. Her father made her siblings spend 15 minutes a day with her, playing cards or other games. She believes this helped her develop social skills, like turn-taking, problem solving, sharing, etc. Xenia recalled the years in her past, from 3rd grade to 10th grade, when she was *made fun of and teased because of not fitting in.* Her interests were very different from the other girls, who wanted to talk about boys, clothes, and music. Xenia was interested in countries, flags, and communism. She shared that she has always disliked reading fiction because *it is not literal enough for her.* She received *LD services in school* but was not officially diagnosed as having autism until she was in college. She has a college degree in Political Science but has never been able to work in a job related to that degree. She has worked in group homes, as a janitor, and has done data-entry work.

Joe

Joe is a passionate and sometimes sarcastic individual, which came through during the interviews. He described himself, early on, as being a runner *and has having echolalic speech. His parents were also told that he* was mentally retarded. *He was diagnosed as having autism at age 3 ½ and again at age 6. His mother diligently worked at finding appropriate school programming for him. He described how he was* placed in an EMH classroom, *even though he* could read the encyclopedias in the room. *He has a great deal of respect for his mother as she was a very strong advocate for him as he was growing up. He described in great detail, about how he was bullied and harassed* every day from 6th grade to 10th grade. *He never wanted to* tell on *the bullies because even then, he knew that it would be worse if he told. He internalized those feelings and shared during the interview that after intensive counseling regarding these incidents, he was able to* forgive his tormentors *after releasing the anger he had internalized. Joe has two Master's degrees and finally has a job where he can utilize those skills, after working at several jobs, most of which he was unsuccessful.*

Eugene

Eugene is several years older than Xenia and Joe but some of what he shared was very similar. When he was growing up, virtually nothing was known about autism. *He, too, was given many labels, including mental retardation, deaf, and* everything else. *He has memories of rocking in his crib when he was a baby and of* making up nonsense songs *of the street names in his city. He shared that he did not like school but did better when he enrolled in a* prepatory school, *which he liked because of* the structure *which he did not have in the public school setting. Eugene has a college degree in Speech Correction but was told by his supervisors that he* needed professional help *and was not allowed to finish student teaching. Eugene talked about the difficulty he has always had in regards to social situations, most especially about relationships with women and finding and maintaining jobs.*

The students in the "Methods for Students with Asperger Syndrome" class enjoyed listening to these interviews.

The following are some of the comments they made regarding the interviews:

- *These were interesting interviews and it made me sad as to how unaccepted these individuals were with their peers. We have a lot of education to do with schools in this area!*
- *These three individuals were very, very interesting to listen to.*
- *I found it interesting to hear him talk about the "refrigerator mother" theory and the influence Bettleheim still had on practitioners in the 70's and beyond.*
- *We learned what really bothers her and that is good and helpful for us as teachers.*
- *It made me very sad that he was picked on and teased so much. That is one*

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thing that I worry about continuously with the kids on my caseload.

- *Listening to these three speak about their lives and what they went through was very beneficial. I hope that it will help me to become a better clinician and not always jump to conclusions about what or why my students are reacting the way they do.*
- *I would like to share these stories with my students and their parents. I think it would be helpful for them to hear about what adults with autism can do.*
- *All three of these interviews were very interesting and helpful. I look forward to hearing more from these people.*

The students in the class had the opportunity to do just that. They read parts of the original study which gave them more information, in addition to the interviews. The second set of interviews included information about the experiences the adults had with their jobs, mental health concerns, unmet needs in the community, and other issues related to being an adult with autism. The assignment for this set of interviews was for the students to send an e-mail to all three of the adults and ask them questions they had after listening to the interviews. The adults replied immediately in almost all cases and shared advice and their own personal thoughts on the subjects. The following are some of the questions and answers:

- Q: *Do you have any suggestions as to how to approach the area of social skills instruction?* A: *My idea is one that has been done for other students and people on the autism spectrum and it is called the circle of support. If people used this, the person on the autism spectrum would learn the proper way to deal with situations.*
- Q: *I asked her what she thought about the teaching strategies of ABA and TEACCH. Her response was that taking the best qualities from both would probably be the most beneficial. She liked the eclectic approach.*
- Q: *I am concerned about a fifth grade student with Asperger Syndrome who is on my caseload. He is trying desperately hard to fit in and be like the other kids. What can I do to help him be educated on autism and how to be a self-advocate?* A: *True, he does need to be educated about autism and how he does things. It is not a sickness, disease, disorder, or all that garbage. It is a different style of thinking, perceiving, and reacting, which comes from a difference in the hardwiring of the brain. We are a minority in a differently hard-wired world.*
- *Q: What can I do to help introduce legislation in my state in regards to law enforcement officers and the problems people with autism have with the law?* A : *In my state, police officers are already being trained in working with people with disabilities, including autism. In your state, it would be practical to have a class for police officers. It should be taught in the police academies of that region.*
- Q: *What could I have done for you if we had met many years ago?* A: *I can't say but maybe you could have done what (*the author*) did in meeting my friends and me to do the study. It would have been a breakthrough in the understanding of those of us with autism. Perhaps now you could be an autism awareness ambassador along with your family.*
- Q: *How can employers modify the work environment to meet the needs of adults with AS?* A: *Whatever sensory problems that particular adult has, modifications can be made. Allowances such as ear plugs being worn can be allowed, maybe not playing the radio would help. Maybe the ringing of the phone could be muffled or the lighting could be changed so it doesn't flicker as much. Also breaking down tasks to incremental steps with detailed instructions helps.*
- Q: *How can I help prepare my students for a job?* A: *The best way for you to prepare students for jobs is to get them strong in their strong areas and gear their teaching towards a certain vocation. No one does well in his or her weaknesses. Find out their strengths and teach to them. I learned through trial and error.*
- Q: *How has medication helped you cope with autism and what advice would you give to parents on this issue?* A: *Parents need to contact a qualified physician, someone who knows about ASD. Parents could also do some research on anxiety to learn more about it. I take medication for anxiety and depression and it is very helpful, especially with noise sensitivity.*
- Q: *What would you advise me to do to help my daughter, who has AS, be successful?* A: *One of the most important things in helping your daughter is accepting her as she is. Appreciate her and say verbally what a good person she is and tell her concretely what she is good at each and every day. Encourage your daughter in the things she is good at. Help her in the area of social skills by breaking*

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things down in itty-bitty steps. And try not to predict her future. Only the good Lord knows what she will do in the future.

Responses from the students included the following after completing this assignment:

- *I loved that assignment! What a neat opportunity to talk to adults with AS!*
- *It was a really good experience and they are a gracious group.*
- *I have learned SO much from them!*
- *It was so great that they were so open and willing to answer our questions!*
- *It really added to the class!*
- *I highly recommend doing this again. They have so much wonderful information to share.*
- *It was a great assignment – I have never been so excited to get e-mails!*
- *I really enjoyed reading about the others' questions and the responses they got back.*
- *I think that by gathering information from them, we are so much better informed and can be "ambassadors" in our school districts.*

Post-course follow-up and recommendations for the future

Since this course has been over, the author was asked if any of the adults would be willing to fly to ND to talk to the students, parent group, and school staff. Initial ideas are being discussed to determine if several districts could contribute to the expenses of airfare and speaking honorariums. A nother student asked the author if one of the adults would be willing to communicate via e-mail with one of his students who was recently diagnosed with Asperger Syndrome and had significant social difficulty as it relates to being manipulated by others. The adult very willingly agreed to communicate with the young man since he understands so well. *I still have problems being manipulated by people,* he responded.

In the future, this author is planning on having these adults with Asperger Syndrome "log on" as co-teachers during the chat sessions and participate during live discussions. It was not possible the first time through this course due to their work schedules.

References

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